

Behavioural data as an adjunct to HIV surveillance data

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Sex Transm Infect 2006;**82**(Suppl 1):i57–i62. doi: 10.1136/sti.2005.016543

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Background: Second generation surveillance for HIV aims to improve the validity and utility of routine serial HIV prevalence data. It includes the collection of data on sexual behaviour and sexually transmitted disease prevalence.

Methods: This paper reviews the function of sexual behaviour data in HIV surveillance and the methods used to determine which behaviours are monitored and how changes in behaviour can be assessed.

Results: Sexual behaviour data provide a poor predictor of the future spread of HIV, but these data can provide corroboration of changes in HIV incidence and assist in attributing changes to particular aspects of risk. Significance tests should be used to assess changes in behaviour, but this requires transparent reporting of methods and sample sizes.

Conclusions: Collection of behavioural data will provide important retrospective information about the HIV epidemic progress and should not be neglected because of the focus on improving HIV sero-surveillance.

It is obvious that the spread of any infection depends upon the contact patterns within the population which provide the route for transmission. In the case of HIV, the relevant contacts are sexual intercourse, sharing of injecting equipment among injecting drug users and, more rarely, using unscreened blood in transfusions and blood products, and repeated use of uncleaned medical equipment. The emergence of the HIV epidemic in the 1980s prompted the collection of interview data on patterns of sexual behaviour both in randomly sampled household based surveys^{1–3} and in convenience samples of particular high risk groups.⁴ Contact tracing studies identified the network of sexual contacts between men who have sex with men who were early cases of AIDS.⁵ Subsequently, case-control and cohort studies identified sexual contact and injecting drug use as the main routes of transmission of HIV. In 1988, the World Health Organization (WHO) Global Program on AIDS estimated that heterosexual transmission accounted for 80% of HIV infections in Africa.⁶ Although the estimate of the contribution of heterosexual transmission in Africa has been disputed by some authors,⁷ there is consensus that sexual transmission of HIV is the main mode (over 95%) of transmission for HIV infection among adults in Africa.⁸ Over time, methods have been developed to evaluate and improve the validity of self-reported sexual behaviours and to measure the most relevant behaviours. However, there are often trade-offs between collecting simple, comparable, and consistent indicators of risk behaviour and developing a detailed and truthful description of the range of behaviours within populations.

From early in the AIDS pandemic HIV sentinel surveillance has been recommended by WHO.⁹ More recently the Joint United Nations Programme on AIDS (UNAIDS)/WHO HIV surveillance working group, in collaboration with other international partners, has updated its recommendations and advocated the implementation of "second generation surveillance".¹⁰ One of the key features of this strategy is to continue monitoring both sexual behaviour and patterns of prevalence of other sexually transmitted diseases, in the expectation that these will assist in understanding the spread of HIV.¹⁰ However, the difficulties inherent in collecting reliable and valid data on sexual behaviour and patterns of incidence of sexually transmitted diseases, and in understanding their relevance for HIV risk have discouraged many programmes from collecting or using such data.

Here, we review the reasons for collecting such data, describe some of the difficulties in interpreting trends in risk behaviour, and identify the potential uses of such surveillance data. As in the rest of this supplement, our focus is on the behaviours of populations where there is a generalised heterosexual epidemic.

WHAT ARE THE DATA SOURCES?

In early attempts to understand the spread of HIV in sub-Saharan Africa, a number of national surveys of sexual behaviour were undertaken^{3, 11} along with more local studies.¹² Subsequently, more regular national population based surveys have been undertaken with the inclusion of sexual behaviour questions in the Demographic and Health Surveys (DHS), supported by the United States Agency for International Development (USAID). Further, many recent DHS also include testing for HIV in what are known as DHS+ surveys. Some countries have conducted national reproductive health surveys among young people that include some knowledge and sexual behaviour questions. These large scale surveys can provide behaviour data at national level to evaluate trends if repeated over time. With a focus on defined subpopulations at high risk for HIV, behavioural surveillance surveys (BSS) were introduced to track trends in risk behaviours over time through multiple rounds of data collection with a consistent, repeatable sampling strategy.¹³

USES OF BEHAVIOURAL DATA DESCRIBING TRENDS

Can we infer the current and future incidence of HIV from behavioural data?

Because HIV prevalence reflects cumulative HIV incidence and mortality it will only slowly respond to changes in risk behaviour. It has been argued that direct measures of risk through behavioural surveys may indicate change sooner before it becomes transparent in measures of HIV infection.¹⁴ However, interpretation of epidemic trends is complicated by our poor understanding of how different social, behavioural, biological, and epidemiological factors influence the dynamics of the epidemic in different settings. The relation between the incidence and prevalence of HIV grows increas-

Abbreviations: BSS, behavioural surveillance surveys; DHS, Demographic and Health Surveys; HIV, human immunodeficiency virus; STI, sexually transmitted infection

ingly complex as the HIV/AIDS epidemic matures and prevention and treatment efforts try to mitigate it at the same time. This translates into an incomplete understanding of the factors driving the HIV epidemics observed in different countries. It is still difficult to explain the considerable differences in HIV dynamics—for example, in southern Africa most countries have quickly reached very high levels of HIV prevalence, and in western or central Africa the epidemic is progressing at a much slower rate.¹⁵ The lack of a clear relation between measures of risk behaviour and HIV incidence make it unlikely that we can confidently predict HIV trends from changes in behaviour. This lack of a clear relation is due to:

- problems in accurately measuring the risk behaviours
- interactions and correlation between many different risk behaviours
- differences between populations in behavioural surveys and antenatal clinic (ANC) surveys in some cases
- the timing of measures of a population's behaviour compared with the historical cumulative incidence reflected in prevalence surveys
- small differences in risk leading to very large differences in HIV incidence when the population is near to the threshold allowing the invasion of the virus.

In the case of any infection, there is a threshold rate of contact which can allow the spread of infection. In the case of a sexually transmitted infection like HIV, heterogeneity in risks means that this threshold can be passed by some individuals and not by others. As the threshold is crossed, the spread of infection increases dramatically, hence the sensitivity of HIV incidence to subtle changes in the risk of the population. The extent of spread will also be controlled by the fraction of the population who have passed through the threshold and how their contacts are distributed (that is, the pattern of mixing between low and high risk individuals).¹⁶ In summary, accurately measuring risk behaviours is a barrier to predictions, but even if we could accurately measure some of the levels of risk in the population, we would still be faced with the difficulties inherent in interpreting that risk.

Interpreting trends in HIV incidence

In circumstances where HIV incidence has changed and can be detected in measures of prevalence then good quality behavioural data collected over time have an extremely important role. Firstly, it can add confidence to the interpretation of prevalence trends. If behaviour has not changed, other factors such as mortality and saturation of the population at risk may explain declines in HIV prevalence. It would be extremely useful to have comparisons of serial cross-sectional behavioural data where we are confident that there have, and have not, been changes in HIV incidence to understand the type and magnitude of change that is associated with continued and obvious reductions in HIV incidence. Secondly, data describing a number of risk behaviours, for example, condom use, involvement in commercial sex, number of sexual partners, and age of sexual debut, would allow us to see which behaviours have changed and which have not and to begin attributing the change in HIV incidence to particular causes.¹⁷ This is particularly important if we are to learn the lessons of success and develop future programmes appropriately. Here, the quality and representativeness of behavioural data are important if objective and unambiguous conclusions are to be derived.

Ideally behavioural data would represent the same populations as those in which trends in HIV prevalence have

been measured. For example, measures of behaviours in cities would be most relevant for measures of trends in HIV in cities. However, where populations are epidemiologically linked, such as when infection is maintained in rural populations through contact with urban dwelling partners, or when infection spreads from older men to younger women, then behaviours from across locations and ages are relevant. Reductions in HIV incidence are likely to appear first in young people such as women aged 15–24 years. This could reflect an increase in the age of sexual debut which could fail to translate into reduced incidence across the population if risk is simply delayed and older members of the population do not alter their behaviour. Before the peak prevalence of HIV we expect infection to naturally saturate, so it is difficult to determine the relative contribution of saturation of infection in those with high risks and changes in risk behaviours reducing HIV incidence. Following the peak we can determine from models how much we expect prevalence to decline due to HIV associated mortality following the epidemic saturating. This allows us to estimate how much the risk has changed and determine if a commensurate change is observed in concomitant behavioural data.¹⁸

Indicators for monitoring and evaluation versus generating a detailed understanding of risk

In studies of sexual risk behaviour, there is tension between indicators for monitoring and evaluation, and variables required for a full, sophisticated understanding of risk within a population. Indicators serve policy makers by measuring the attainment of programme goals, and need to reflect those goals accurately and sensitively. Indicators have to be simple to measure and understand and have to be collected consistently to allow comparisons across populations and over time. The main limitation of indicators is that they tend to be determined and influenced by the willingness of people to answer specific and very personal questions about their sexual behaviour.

Despite their limitations, a simple set of sexual behaviour indicators has been composed and adopted by a wide range of international and national organisations.¹⁹ The exact definitions and constituents of this set can be debated, and they are often expanded for the purposes of particular programmes. However, if these indicators are changed, there are enormous costs in terms of comparability, particularly over time. In some cases, earlier measures can be recovered from subsequent developments of questions. For example, if we were to ask how many different sexual partnerships one had been in over the previous 12 months, then from the distribution of numbers of partners it would be possible to estimate the fraction with more than one partner. To recover the generally agreed indicator for adults, of sex with non-cohabiting partners,¹⁴ we would also have to ascertain the number of cohabiting partnerships one had been in over the previous 12 months. However, great care needs to be taken since the biases in response may change according to how questions are asked and interpreted. Some example indicators that can be used to assess levels of knowledge and of sexual behaviour in the population are:

- Percentage of respondents sexually active in the last 12 months who have had sex with a non-marital, non-cohabiting partner in the same period.
- Percentage of respondents with a non-marital, non-cohabiting partner who say they used a condom the last time they had sex with that partner.
- Percentage of young people (15–24 years old) who have had sex before the age of 15.

- Proportion of young women who have had sex in the preceding 12 months with a partner who is 10 or more years older than themselves.
- Percentage of men reporting sex with a sex worker in the last 12 months.
- Percentage of these men reporting condom use the last time they had sex with a sex worker.

In understanding the indicators and making them comparable, the relevant denominator populations for each of the reported behaviours are vital. The relevant age groups are young men and women (15–24 years old) and adult men and women (15–49 years old). Care needs to be taken that, when indicators are reported, they apply to the same population. Thus, reported condom use at last commercial sex applies to those who report commercial sex, and condom use at first sex applies to those who have ever had sex. Further, the percentage of sex acts protected by condoms measures the proportion of sexual exposures that is considered to be safe, but this does not reflect the absolute number of sex acts that place individuals at risk. For example, 10% condom use in 10 HIV associated sexual episodes includes 9 events with a risk of transmission compared with 75% condom use in 100 HIV associated sex episodes with 25 events.

The requirement for a standard and simple set of indicators is at odds with the true complexity of sexual behaviours. The average behaviours of the population and the proportions of the population with particular attributes—for example, the proportion who use condoms, the proportion frequenting commercial sex workers or the proportion who have non-cohabiting partners are particularly poor measures of a population's risk. There is extreme heterogeneity in numbers of sexual partnerships, sex acts within partnerships, condom use within those acts, the sequence of acts with different partners, and the characteristics of those partners.^{20–22} The measurement of the distribution of these behaviours, their interrelationship in the individual, their dependency on the behaviour of others within the interacting population, and their relation to the risk of acquiring and transmitting different STIs are all areas for research.²²

Such research is also focusing on the methods of ascertaining valid reports of risk behaviour using self-administered questionnaires and computer assisted and semi-structured interviews, along with a range of measures to gain the confidence of study participants.^{23–25} Concomitantly, research is also assessing the best way of measuring relevant behaviours—for example, to understand behaviours within sexual partnerships and the characteristics of sexual partners a number of studies have focused on attributes of recent sex partners.^{23–26} In addition, the way individuals estimate the frequency of events such as sex acts and condom use, counting individual events or basing responses on general rules, have been investigated, and appropriate time periods depending on method of response and the frequency of events have been developed.²⁷

Other studies using methods of contact tracing, snowball sampling, and a novel form of respondent driven sampling have investigated the detailed structure of the sexual partner network in developed countries.^{28–29} These resource intensive studies have illustrated the importance of dense parts of the sexual network in the persistence of STIs, but the role of particular details of network paths is still an area for speculation. Such detailed studies, although of great scientific interest, as yet have little relevance to ongoing national efforts at behaviour surveillance.

Individuals with greater numbers of partners drive the epidemiology of HIV but are less likely to appear in behavioural surveys if they have dysfunctional or difficult lives, and also less likely to be able to report reliably

quantitative measures of risk.³⁰ Their importance will be ignored if we use dichotomous measures of risky behaviour, such as those with and without non-cohabiting partners, and their low numbers will introduce large statistical errors in estimating their behaviours in randomly sampled population based surveys. This argues for focused surveys measuring the risks of high risk groups (for example BSS methodology). However, this creates other problems of assessing the fraction of the wider population in high risk groups and how representative those captured in the surveys are of these groups as a whole. The risk behaviour of both those infected with HIV and those susceptible to the infection are important to the continued spread of infection. The epidemic of HIV will reach a prevalence where it has saturated in those with high risks of infection. At this point, the basic reproductive number, the number of new infections caused by an average infection in an entirely susceptible infection, is reduced to an effective reproductive number of one or less because infectious contacts are “wasted” on those already infected.³¹ Whether prevalence stabilises or declines will depend on the risk behaviours of susceptible young people entering the sexually active population. Thus, the age of sexual debut, and the subsequent sexual behaviour of young people, should be a focus of studies monitoring risks of HIV.²²

Can we determine the importance of particular behavioural variables?

Studies of behavioural indicators as risk factors for individuals acquiring HIV infection have found them poor and inconsistent markers of risk.¹⁴ However, such an analysis fails to consider their importance and role in the population as a whole. If we are interested in the potential for acquisition and transmission of HIV and its propagation then case-control study of risks is not a good way to determine indicators for a number of reasons:

- (1) An individual's risk depends upon the stage of the HIV epidemic. The probability of a sexual partner being HIV infected will depend upon the prevalence of HIV infection in the pool of partners. Furthermore, HIV transmissibility depends upon the viral load of the infectious partner and hence the stage of HIV infection. A recent local outbreak will expose individuals to a higher risk of transmission than a longstanding epidemic.
- (2) There are likely to be misclassification biases that are virtually impossible to eliminate in case-control studies. An individual's risk of acquiring HIV depends on whether their sexual partners are infectious. This in turn depends on the partner's behaviour and the wider network of sexual contacts in which they are located. The distribution of contact patterns of individuals and their choice of sex partners tells us something about the structure of the network but the location of an individual within it will not be revealed by the individual's reported behaviours.
- (3) Case-control studies only measure the individual's risk of acquiring infection, which is a function of whether their partners are infectious. It does not measure the risk of an individual transmitting the infection to others. The onward transmission of sexually transmitted diseases has been shown to be more a function of the individual's own behaviours,³² but this will not be reflected in a study of their risks of acquiring infection.
- (4) The incidence of HIV within the population is a function of current risk behaviours putting individuals at risk of infection. Due to the long period between infection, AIDS, and death, case-control studies of prevalent HIV infections measure the cumulative risk of acquiring HIV, not recent risk behaviours.

- (5) The interactions between risk behaviours can mask the importance of variables. The classic example of this is the association of acquiring HIV with condom use, since those with high numbers of partners or partners who are likely to be HIV infected are more likely to use condoms.²²

Case-control studies and prospective cohort studies of individuals can indicate how HIV is transmitted, but, to develop behavioural indicators, we need to move to a population level. Unfortunately, comparisons of populations with high and low prevalence of HIV infection have failed to provide good behaviour measures explaining the differences. This could be due to retrospective studies measuring behaviours that have already changed due to mortality, concern about HIV, or other societal developments. Alternatively, it could be that the studies have failed to measure accurately the important behaviours or have failed to capture the key individuals with very high risks which drive the epidemiology of HIV.

Without clear observed correlates of the scale of the HIV epidemic and potential indicators, we are left to construct descriptions of a population's risk from our understanding of the transmission of the virus in models of HIV transmission. Theoretically, we can determine the proximate behaviours which expose an individual to the risk of acquiring or transmitting HIV.^{33–34} Our measures of sexual behaviour must either represent these proximate determinants directly or capture variables closely correlated with them. The observed relation between the number of unprotected sexual acts within a partnership and the transmission of HIV, where the risk of acquiring infection is high in the first few acts and then plateaus, suggests that there is extreme heterogeneity in the transmission probability across partnerships.³⁵ The most likely explanation is that there is a high risk of transmission in partnerships where the infectious partner has a high viral load.³⁶ This means that the number of sexual partners is a more important variable determining risk of HIV spread than the number of sexual acts and that consistent condom use is much more important in preventing spread than occasional condom use.³⁵ Theoretically, we know that an infected individual can only transmit infection onwards if they form new sexual partnerships or have multiple current partners. Hence rates of sexual partner change and the overlap between partnerships are the crucial measures of risk. Reports of commercial sex and non-cohabiting partners represent behaviours that are associated with high numbers of sex partners in either the individual or their contacts. To understand how observed distributions of proximate determinants of HIV translate into spread of the virus in the population we can use mathematical models.³⁷ However, as described above, the sensitivity of the system combined with the error in measurements allows little confidence in forecasts.

How do we assess whether there has been a significant change in behaviour?

For evaluating trends in risk behaviour, there are standard statistical techniques which can be used to assess whether a change over time is significant, such as a χ^2 test for a trend in a proportion, a least squares regression for behaviours that are normally distributed, and transformations or nonparametric tests where this is not the case.³⁸ Such methods work when the individuals interviewed are independent at each time point and this will often be the case with serial cross-sectional data. However, if the same individuals are measured repeatedly, then other methods, such as general estimator equations are more appropriate.³⁹ Such statistics require knowledge of sample sizes, which should be reported. Statistical tests should be used to determine whether

observed differences in behaviour between time points are more than would be expected by chance if we are to have any confidence in reported behaviour change. However, beyond statistical significance based on excluding random error, we have the problem of biases in results which may change over time. These biases include whether the sample represents the same population over time, and knowledge of the sampling frame, response rate, and causes of refusal over time are important. A change in survey method—for example, from face to face interviews to self-administered questionnaires—could alter disclosure of behaviours, so similar methods should be compared over time. Further, social desirability biases could change over time. This was found in two consecutive national surveys in the UK, where questions in both surveys relating to the period before the first survey detected an increase in reported average risk that could only represent a change in willingness to reveal behaviours such as same sex encounters over the decade between the studies.⁴⁰ A similar change was observed in Zambia where the proportion of individuals reporting sex before age 15 years in the DHS fell between 1996 and 2001/02, a change only possible through altered reporting.⁴¹ In generalised HIV epidemics, a concern is that, as individuals learn that high risk behaviours expose them to a risk of HIV, they may be less willing to reveal such behaviours in interviews.

Our ability to detect a change in risk to determine the stability of new levels of risk will depend upon the indicator used (for example age at first sex *v* number of casual partners, condom use, number of partners in last six months, or commercial partners), as they will change at different rates and represent different durations. For instance, change in age at first sex will take longer to become apparent compared with condom use in last sex act with commercial sex.

To detect alterations in risk behaviour it is clearly important that surveys span the period of change. Well spaced out surveys are more likely to capture changes than those too close together in time. However, our ability to rapidly interpret changing HIV prevalence is assisted if behaviour surveys follow shortly after. Where change in HIV incidence and prevalence is likely to evolve slowly, as in the general population, behaviour surveys spaced out on a period such as five years would be appropriate. In high risk groups such as sex workers, where the change in incidence could be rapid, more frequent surveys—for example, every year—would be warranted.

In determining the significance of a change in risk behaviour repeated surveys could add statistical power but significance is more a function of sample size and size of the effect. Repeated surveys are more important in distinguishing between transient and lasting change, which may be particularly important in volatile political and economic settings. The statistical analysis of repeated surveys can be enhanced if the variation in reported risk behaviour can be partitioned between individuals and higher level groupings, such as locations or times of surveys. Such multilevel statistical models can help interpret the relation between proximate and distal influence of risk.⁴²

Perhaps a more important question than whether a change is statistically significant is whether the change in risk behaviour is relevant. A modest change in condom use or partner numbers may be significant when comparing two large population surveys with a high power. However, the size of the change may have to be greater and more widespread to be epidemiologically significant. Again, this can be assessed by comparison with observed changes in HIV incidence and through mathematical models predicting the epidemiological impact of the change. Such models fitted to HIV trends and parameterised with behavioural data allow us to attribute changes in incidence to particular changes in

behaviour. How these are then related to changes in social norms or specific interventions is a further question. Changes in reported behaviours associated with social desirability bias (as opposed to actual changes) are still of interest, since a dramatic change in reported behaviours due to such bias is likely to reflect changing norms and expectations of behaviour.

The HIV epidemic could change behaviour directly through mortality following the acquisition of AIDS of those with high risks.⁴³ Further, opportunities to form sexual partnerships will be altered as AIDS deaths alter the demographic and behavioural distribution of the population.⁴³ In such circumstances, the behaviours of young adults newly entering the sexually active population are likely to better reflect trends in social norms and the decisions people make. The cause of these changes could be health promotion or exposure to death associated with AIDS, which could be explored in analyses of exposure to funerals and death of relatives.

OTHER SEXUALLY TRANSMITTED DISEASES

Surveillance and reporting for other STIs is recommended in second generation surveillance.⁴⁴ Monitoring trends in STIs in the general population or specific target groups is the primary purpose of STI prevalence surveys, and the availability of accurate diagnostic tests for several common STIs has made such population based surveys more feasible. Such surveys are recommended in part, because other STIs are likely to enhance susceptibility to and transmissibility of HIV, and also, because shared risk behaviours mean that these provide biological markers for changes in HIV risk. This is complicated by the availability and success of curative treatment for bacterial STIs and trichomoniasis which can alter the incidence of these infections in the absence of changing sexual behaviour. Thus, the incurable viral STI herpes simplex virus type 2 (HSV-2) provides a better marker of risk,⁴⁵ but only if incidence of infection is monitored. Since most infections remain asymptomatic, either repeated serological surveys or serological surveys in the young who are recently sexually active are required. As for HIV, the relation between the STIs and particular behaviours is uncertain. It has been argued that a long duration STI with a low transmission probability per act, like HSV-2, will be a better marker for HIV than a short duration high transmission probability infection such as gonorrhoea, chlamydia, or syphilis.⁴⁶ However, the importance of the primary viraemia in HIV suggests that the virus shares some of the epidemiological characteristics of the latter STIs—that is, those which are short lived with a highly transmissible period—as well as those of the former type—that is, STIs with a long incurable period where there is a low transmission probability.³¹ More research is required to understand these relationships. Nonetheless, a high incidence of other STIs does suggest a problem that needs to be addressed if the spread of HIV is to be controlled, and the other STIs should be taken seriously in surveillance programmes related to HIV. To further our understanding testing for a range of STIs should be included in surveys measuring HIV and sexual behaviour. However, this could prove expensive and requires additional biological samples. Rather than jeopardise well established and successful surveys like the DHS, separate surveys or pilot studies would be sensible to determine how well we can collect and interpret STI data.

CONCLUSIONS

It is perhaps not surprising given the uncertainties described above and the need to improve HIV sero-surveillance itself that countries have failed to invest extensively in behavioural surveillance. Furthermore, as we have described, the use of

such data is likely to be more productive in retrospective analyses than in predicting future spread of HIV. Nonetheless, we believe that behavioural data are important if we are to understand and generalise the experiences of success in reducing the spread of HIV. In addition, behavioural surveillance has an important role in describing the patterns of risks that should be the target of interventions. Our focus here has been the epidemiology of HIV. Over 20 years, we have learnt a great deal about the complex relations between behaviours and HIV, but further research is still required. At the same time, much of the role of behavioural indicators centres on programmatic goals and evaluation. The collection of consistent indicators is therefore important in the design and evaluation of the large scale programmes being established to harness the hoped for synergies between HIV treatment and prevention.

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GPG thanks the MRC, Wellcome Trust and UNAIDS for Grant Support, SG thanks the Wellcome Trust for grant support.

Competing interests: none declared

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